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# **The experiences of people with fatigue after stroke: A qualitative evaluation from the Nottingham Fatigue After Stroke (NotFAST) study**

**Submission category:** Original research

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## **Abstract**

### **Background/Aims**

Post-stroke fatigue is common and impacts on patient outcomes. Our aim was to investigate day-to-day experiences of fatigue six months after stroke.

### **Methods**

Participants were identified from a cohort study of fatigue (NotFAST) which excluded those with depression and aphasia. Participants who reported high fatigue scores at six months post-stroke were interviewed individually. Data were analysed thematically.

### **Findings**

Twenty-two participants were interviewed. Fatigue was reported to impact on instrumental activities of daily living, leisure activities, social relationships and work life. Variations in fatigue were reported throughout the day and over the longer term. Triggers included physical and mental exertion, and periods of inactivity. Self-devised management strategies included daytime rest or sleep, pacing activities, making compromises, accepting help from others, and keeping active. It was sometimes unclear whether fatigue was a specific result of stroke or due to ageing, poor health, or sleep disturbance. Few participants had received specific information or advice about fatigue.

### **Conclusions**

Fatigue is an important issue, even after mild stroke. Stroke survivors felt ill-equipped to manage their fatigue and often struggled to adapt. There is a need for improved information provision and educational interventions to prepare survivors for the impact of fatigue.

## Introduction

Fatigue after stroke is common (Lerdal et al., 2009; Choi-Kwon and Kim, 2011) and differs qualitatively and quantitatively from pre-stroke fatigue (Annoni et al., 2008; Kirkevold et al., 2012; Eilersten et al., 2013). Patients report that post-stroke fatigue is characterized by weariness unrelated to previous exertion levels and is usually not ameliorated by rest (Staub and Bogousslavsky, 2001; De Groot et al., 2003). A qualitative meta-synthesis of stroke survivors' experiences of fatigue (Eilersten et al., 2013) identified five core characteristics of post-stroke fatigue: (i) a lack of energy to perform activities; (ii) an abnormal need for long-lasting sleep; (iii) being easily tired by activity, along with an abnormal need for naps or rest; (iv) unpredictable feelings of fatigue without explanation; and (v) increased stress sensitivity.

Post-stroke fatigue is an important issue for stroke survivors and their carers (McKevitt et al., 2011). It can have a negative impact on survivors' physical, psychosocial and psychological functioning (Choi-Kwon et al., 2005; Barker-Collo et al., 2007; Winward et al., 2009; Northcott and Hilari, 2011; Andersen et al., 2012; Northcott et al., 2016), participation in rehabilitation (Morley et al., 2005; Wu et al., 2015a), and rates of institutionalization and survival (Glader et al., 2002). However, post-stroke fatigue is also a hidden and undefined condition, with a lack of knowledge about its existence and its impact (Eilersten et al., 2013).

Given the impact of fatigue on outcomes for stroke survivors, it is important that post-stroke fatigue is appropriately identified (van der Werf et al., 2001) and managed (Gordon et al., 2004) in clinical practice. However, there is currently a lack of evidence or clinical guidelines for the management or prevention of post-stroke fatigue (McGeough et al., 2009; National Institute of Health and Care Excellence, 2013; Wu et al., 2015b). In a survey of stroke survivors, 43% of respondents reported that they did not feel they were receiving the help that they needed in dealing with fatigue (McKevitt et al., 2011).

The qualitative studies that have been specifically conducted into post-stroke fatigue have been few in number. Of a qualitative meta-synthesis of 12 studies of stroke survivors' experiences of fatigue (Eilersten et al., 2013), only four studies explicitly identified fatigue in their aims (Flinn and Stube, 2010; Barbour and Mead, 2012; Kirkevold et al., 2012; White et al., 2012). Results of these studies indicated that fatigue has a significant impact on the lives of stroke survivors, including engagement in meaningful activities, life roles, cognition, and participation in rehabilitation. Other qualitative studies of stroke, which have included aspects of post-stroke fatigue, have reported similar findings (Bendz, 2003; Röding et al., 2003; Carlsson et al., 2004;

Carlsson et al., 2009; Robison et al., 2009; Thompson and Ryan, 2009). However, few studies have explored the experience of post-stroke fatigue to illuminate the day-to-day problems and difficulties faced. There is also little information about other aspects of post-stroke fatigue, such as factors that might exacerbate or improve fatigue, or strategies that people may use to manage their fatigue.

The aim of the present study was to explore the day-to-day fatigue-related experiences and perspectives of participants who reported high levels of fatigue at six months following stroke in the Nottingham Fatigue After Stroke (NotFAST) study (Drummond et al., 2017).

## **Methods**

### **Design**

The study was approved by the East Midlands (Nottingham 2) NHS Health Research Authority Research Ethics Committee (13/EM/0187). All participants provided informed consent.

Potential interviewees were identified from participants in the NotFAST study (Drummond et al., 2017). This was a multi-centre longitudinal cohort study to investigate post-stroke fatigue and its associated factors in patients who did not have high levels of depressive symptoms or aphasia. NotFAST participants were identified from patients admitted to four UK inpatient stroke units within four weeks of stroke, between September 2013 and March 2015. Those eligible for inclusion had a clinical diagnosis of stroke, were aged 18 years or over, able to give informed consent, and had no previous history of stroke. Potential participants were excluded if they were unable to read or speak English or had a documented diagnosis of dementia. Following initial screening, patients who had significant depressive symptoms (scoring  $\geq 7$  on the Brief Assessment Schedule Depression Cards (BASDEC) (Adshead et al., 1992)), or who scored below the age-recommended thresholds for dysphasia (Sheffield Screening Test for Acquired Language Disorders (Synder et al., 1993)), were also excluded from the study.

In the NotFAST study, 268 participants were assessed within four weeks of first stroke on the Fatigue Severity Scale (FSS) of the Fatigue Assessment Inventory (Schwartz et al., 1993), and 213 were re-assessed at six-month follow-up. Of these, 109 (51%) reported significant levels of fatigue (FSS  $> 36$ ).

## Procedure

From the 109 participants who had reported significant levels of fatigue at six months in the NotFAST study, we recruited participants from the two closest recruitment sites to the research team office base (Nottingham University Hospitals and University Hospitals of Leicester). We approached both men and women, some who were working at the time of stroke, and some who lived alone. We estimated that data from approximately 20 participants could be obtained and analysed within the available timeframe.

Although participants had already consented to being approached about potentially participating in this qualitative study within the NotFAST study, further informed consent was obtained for the interviews. Participants were interviewed in their own homes by one of three interviewers, all of whom had had prior experience of conducting qualitative research interviews. A semi-structured interview schedule was developed, based on extant literature and input from the study Steering Group, which included stroke survivors. Open-ended questions were used in order to give participants the opportunity to talk freely about the topics covered, and participants were able to introduce topics relevant to post-stroke fatigue. The interviewers used clarifying questions and prompts where appropriate to further explore the participants' experiences. Participants were initially asked, '*You have indicated that you have experienced fatigue. What does it feel like?*' Prompts for this question included: '*How often do you feel fatigued?*', '*How long does it last?*', and '*When does it occur?*' Further questions posed were: '*How does the fatigue affect you in daily life?*', '*What things make you more fatigued? Or less fatigued?*', and '*Has anyone talked to you about fatigue?*' Synonyms for fatigue (e.g. 'tiredness', 'exhaustion', 'lack of energy', 'weariness') were used by interviewers where appropriate in order to aid understanding.

Interviews were digitally recorded and transcribed verbatim. Transcripts were checked against the original audio recording and any errors were corrected.

## Analysis

The data were analysed by two of the researchers using thematic analysis, following Braun and Clarke's (2006) guidelines. Our aim was not to achieve data saturation or exhaustion of themes; rather, we aimed to identify sufficient key themes to adequately reflect the textual data from the interviews, focusing on the salient points emphasised by participants during the interviews.

The transcripts were initially read and re-read, to enable the researchers to familiarise themselves with the depth and breadth of the data and the types of experiences conveyed. Initial data codes were then generated, identifying commonly-occurring concepts and issues arising from the data. All transcripts were searched to further identify these codes. Different codes were then rearranged into overarching themes. Another researcher was available in any instances where there were any differences of opinion which could not be resolved by the interviewers. According to Braun and Clarke's (2006) recommendations, a theme was considered to represent an important aspect of the studied experience and also showed a pattern across the data. Codes were compared and contrasted to look for similarities and differences between different participants' responses. Quotations were identified which illustrated examples of the agreed themes.

## **Findings**

### **Characteristics of participants**

Twenty-five participants were invited to take part in the qualitative interviews. Two declined to be interviewed, and one agreed to participate but could not subsequently be contacted. The 22 who took part were aged between 51 and 83 years (mean = 68.8 years, SD = 9.32), and 12 were men (54.5%). Twenty (90.9%) participants were white British; 17 (77.3%) were retired/no longer working; and 17 (77.3%) lived with a spouse or other person.

At six month follow-up, the mean fatigue score (FSS) was 49.91 (SD 8.79), indicating high levels of fatigue. The mean depressive symptoms score (BASDEC) was 3.38 (SD 2.96), below the cut-off score of  $\geq 7$  for depressive disorder. Stroke severity was minor to moderate (mean Nottingham Extended Activities of Daily Living scale (Nouri and Lincoln, 1987) score 16.55 (SD 5.42); mean Barthel Index (Wade and Collin, 1988) score 17.64 (SD 2.67)).

Interviews lasted between nine and 63 minutes, with a mean of 26 minutes.

### **Key themes**

Six major themes were identified from the research interviews, in line with the topics of questioning. These are explored below, with excerpts from the transcripts to highlight participants' experiences.

### ***i. Diverse descriptions of post-stroke fatigue***

Participants described overall reductions in drive, stamina and energy levels. Fatigue was described as being debilitating and all-encompassing.

*"Like, you know, a coil, it sort of winds down and then there's no further energy left for movement, and that's just how it feels." PP1044, female, 67 years*

Many distinguished between *physical fatigue* - often brought on by activity and including bodily sensations and an overwhelming need to rest, and *mental fatigue* - including cognitive slowing and difficulty sustaining conversations.

*"It's sort of like a tiredness, of body and then also of mind as well." PP1088, male, 74 years*

Fatigue was unpredictable. Variations in symptoms were reported throughout the day, and from one day to the next. Some participants experienced feelings of fatigue continuously, while others had more intermittent symptoms and experienced some periods of respite.

*"Sometimes it catches me 'on the hop', I don't know why, I can't explain it. And come the next day, back to normal. It's not consistent, you know." PP1072, male, 75 years*

*"It's there all the time. You don't really feel any different at any point." PP1100, male, 73 years*

*"It's spasmodic. Not all that long. I sort of come round from it quite well." PP1033, female, 83 years*

The onset and progression of fatigue varied between participants. For some, fatigue had been more of a problem in the earlier days after stroke, but for others, the onset – or perhaps its noticeable impact on lifestyle and role performance – was later. Some participants noted that their fatigue had improved over time, but others felt that this was not the case; they had either not improved at all, had reached a plateau, or were experiencing only very slow and gradual improvements.

*"When I got home [from hospital]..., by the time I'd walked from the lounge to the kitchen and made myself a cup of tea and come back again I was really tired... I couldn't do much at all for two weeks, but then it gradually got better and better." PP1026, male, 69 years*



*"I don't think I was as tired when I initially had the stroke... I think I got more tired later on, but I don't know when." PP1100, male, 73 years*

## **ii. Daily impact of fatigue**

Fatigue was reported to affect overall activity levels. More time was spent sitting down in the daytime, and many participants felt there was little time and/or energy left for other pursuits once they had managed to carry out essential day-to-day tasks and rested as much as they needed to.

*"It cramps your lifestyle, 'cause it cuts out a chunk of the useable day and that's annoying and frustrating." PP1044, female, 67 years*

Few participants reported that fatigue impacted on basic activities of daily living (ADLs, e.g. washing, dressing), but many mentioned that instrumental activities of daily living (IADLs), such as housework and shopping, were affected, and that these now took up much more time than previously.

*"Like the days I go shopping, when I come back and by the time I've unloaded, I've put everything away and everything, I'm flaked. I'm tired out." PP1033, female, 83 years*

Mobility was a problem for many participants, both within the home and when out and about. This appeared to be affected by fatigue, rather than solely being a direct physical impact of the stroke.

*"For me, going down stairs, or even in the lift, and going back to the car, that would be taking my energy." PP1044, female, 67 years*

Fatigue had an adverse impact on participation in hobbies, leisure pursuits, and social activities, and resulted in an overall 'narrowing of horizons', reduced enjoyment, and less time spent on previously valued activities.

*"It was my grandson's birthday on Sunday... [There was] a huge party... It was fabulous but my tiredness spoilt it and that was annoying." PP1099, female, 67 years*

Participants who were still of working age mentioned that fatigue had adversely impacted on their working lives. Others felt that, if they had still been required to work, they would be unable to do this, or would find it very difficult.

*"[At work] I used to do twelve hour shifts, but now I do eight hour shifts." PP1035, male, 52 years*

*"If it [the stroke] had happened to me earlier when I had been working and had to go back to work, I don't know how I'd have coped really, 'cause being retired you can organise your days... You can get up sort of gently, not rush." PP1044, female, 67 years*

A broader impact of fatigue related to participants' emotional responses to experiencing fatigue. In particular, many were frustrated and annoyed at the intrusion of fatigue into their lives.

*"Not being able to do what you could do, and the frustration of that ...'How can I let this thing happen to me?' is what hurts the most." PP1001, male, 70 years*

Many participants made unfavourable comparisons with their lives pre-stroke, and felt that their self-identity had been changed by fatigue and they had lost a part of who they had previously been.

*"I've lost that bit of enthusiasm, you know what I mean? That's weird. Because, as I say, people know me as getting things done." PP1035, male, 52 years*

### **iii. Factors found to exacerbate fatigue**

Whilst some participants were unable to identify specific triggers for their fatigue, others felt that it appeared to be related to physical or mental activity.

*"It just comes and does what it wants. There's nothing that sets it off." PP1031, male, 57 years*

*"If I do something on one day I suffer the next day... Yesterday we went to see an old friend in hospital... I didn't feel shattered yesterday, but I do today." PP1088, male, 74 years*

For some, physical exertion was a trigger for fatigue, and active pursuits such as completing household tasks or walking outdoors resulted in periods of exhaustion later that day or, quite often, the following day.

*"I can walk probably three miles with the dog, but the day after I've had it." PP1100, male, 73 years*

Some found that cognition was affected by fatigue, and that concentrating and holding conversations with others were tiring. A number of participants mentioned that taking part in the research interview itself brought on feelings of fatigue.

*"I find the other thing that makes me tired is intense talking... It seems to sort of hit your brain all over the place and you think, 'Gosh I'm tired'. You don't realise it while you're there, but at the end of it, I suppose it's the effort of concentrating," PP1044, female, 67 years*

Another reported trigger for fatigue was periods of inactivity, or sedentary activity, such as sitting down whilst watching television or reading a book. Thus, as well as being a strategy for managing fatigue, spending time resting during the daytime could also serve as a trigger for experiencing fatigue. Many participants mentioned that they tended to fall asleep if they sat down, regardless of the time of day.

*"You're just sitting watching television and suddenly it's a different programme [you're watching]." PP1058, male, 80 years*

#### **iv. Self-management strategies for fatigue**

Participants developed a variety of strategies to assist them in managing their symptoms. Most reported spending time resting or sleeping during the daytime as a common way of replenishing or conserving energy. Sometimes it appeared that these periods of rest were more of a 'necessity', rather than a conscious or necessarily effective strategy for managing fatigue.

*"I'll have to [have a nap], otherwise I won't be able to go out tonight." PP1044, female, 67 years*

For most, incorporating periods of rest in their day was found to be helpful, and meant that they were able to resume valued activities later in the day. However, for others, the benefits of rest were short-lived and their fatigue returned soon afterwards.

*"I feel a bit better then [after resting], but once I get up and start going again, I'm tired." PP1025, female, 79 years*

Many participants reported that pacing activities – spending shorter periods of time on activities and interspersing these with periods of rest – was an effective way of conserving energy and managing daily tasks.

*“I tend to do things, and then I’ll sit down and read a book for a bit, or a magazine, or do a crossword or something, and then get on and ‘do’.” PP1004, female, 75 years*

*“[With gardening] I have to keep stopping. Really short spurts. Whereas you could spend all day, now I’ll probably perhaps do an hour and then I’ll stop and then maybe start again a bit later.” PP1099, female, 67 years*

A number of participants mentioned that they no longer felt able to plan activities in advance, since they could not predict how much they would be affected by fatigue on any given day. Instead, a more flexible approach was generally adopted, often involving rescheduling activities, adapting daily routines, and a degree of trial and error.

*“I don’t plan things now, which is weird. I used to plan weeks in advance, but now... I take each day as it comes.” PP1035, male, 52 years*

Many participants reported that they tried to avoid putting pressure on themselves, and were now undertaking fewer tasks each day and/or ‘letting go’ of some tasks altogether. Many participants reported that they had altered their expectations and made compromises regarding how well, or how often, household tasks were carried out.

*“I don’t push myself too hard now. If it’s not going to get done today, then fair enough, it won’t get done.” PP1121, male, 53 years*

Help from other people was a commonly-used strategy for managing the limitations that fatigue placed on them. This included help from family members, friends and neighbours, and sometimes paid help. For some, the need for help from others meant that expectations of themselves by their significant others had changed, and they had lost some of their former independence and autonomy.

*“We do a bit of shopping and that’s tiring, you see, I can’t do that on my own. I haven’t driven into town on my own and then gone around [the] shops and come home, ‘cause I can’t do that. I need somebody there to say.., ‘I’ll take these bags to the car, so we’re not carrying them all around’. PP1044, female, 67 years*

Some participants found items of assistive equipment useful in managing feelings of fatigue while carrying out daily tasks.

*"The Red Cross very kindly brought me a perching stool which it is still in the kitchen and I still use it sometimes, because when I am chopping I think, come on sit down, you're feeling tired, rest your legs." PP1044, female, 67 years*

Whilst most participants were spending significant amounts of time in the day resting, for some it was also the case that keeping physically and socially active, and avoiding a lifestyle that was entirely sedentary, were important in managing fatigue. Keeping active appeared to confer benefits in terms of boosting energy levels, and also served as a distraction from fatigue.

*"If we go out, I won't fall asleep while we're out or anything like that. I'm fine when I'm out." PP1031, male, 57 years*

Similarly, while undertaking fewer tasks each day was often used as a strategy to manage fatigue, a number of participants felt that they needed to actually put in increased effort and push themselves each day in order to try to overcome fatigue and minimise its impact.

*"It's dead easy to say no, and I try not to do that. I try and push myself all the time, and that's what I've been doing... It's dead easy to do nothing, but I won't." PP1121, male, 53 years*

## **v. Causes of fatigue**

Participants were asked whether they had any feelings about what might be causing their fatigue. Some suggested that fatigue might be, at least in part, due to ageing, poor health, or medication, rather than solely a direct impact of stroke.

*"It could be the pills I'm on for my blood pressure....I mean, they often say they might make you drowsy." PP1031, male, 57 years*

A large number of participants reported experiencing sleep disturbances, and felt that this contributed significantly to their fatigue.

*"I don't sleep very well... Sometimes if I wake up about three o'clock..., I wake up as if I've been asleep all night... I'm so wide awake I know that it's impossible to drop back off to sleep again." PP1049, female, 79 years*

Other participants felt unable to pinpoint a clear cause for their fatigue, or felt that it perhaps had multiple causes that were difficult to separate out or identify.

*"I just presume it's all the different things combined, you know, it's not just one thing. PP1004, female, 75 years*

#### **vi. Lack of information and advice received on fatigue**

The overwhelming majority of participants had received no advice – either spoken or written – from healthcare professionals about managing their fatigue, either in hospital or since discharge.

*"I don't think anyone has spoken to me about it." PP1026, male, 69 years*

It was suggested that, in the acute care phase, fatigue may not yet be seen as a priority. Other aspects of recovery may be of more immediate concern, and patients in hospital may not feel that this is the right time or place to talk about their symptoms.

*"I suppose [in hospital] they were more concerned with getting me on my feet and getting my independence back, and the fact I didn't have to call somebody to walk with me down to the loo and all that in the middle of the night." PP1033, female, 83 years*

The small number of participants who mentioned that they had received advice on fatigue while in hospital said that this mainly concerned accepting fatigue as normal, getting sufficient rest, maintaining sleep hygiene, and adapting to one's altered capacities post-stroke.

*"If I remember rightly [I was told in hospital], 'When you do have a stroke, the body has its own mechanisms. You've had something drastic and it takes time to heal, and the fatigue is part of that healing process'... Mainly just common sense stuff." PP1121, male, 53 years*

Similarly, the small number of participants who mentioned that they had received advice on fatigue since being discharged home said that this concerned accepting fatigue as normal. The

implication was that fatigue would improve over time, and that it was important to manage expectations as to the rate of recovery. The fact that prevention of further strokes is a key concern of treatment post-stroke may have meant that fatigue (and other subtler problems) had been overlooked.

*"I think all [the GP] has gone along with are recommendations from the hospital about medication... I wouldn't say fatigue has been high on the list... She's never said to me, 'Are you suffering from fatigue?' Her role has been to get my blood pressure down."*  
PP1033, female, 83 years

Only two participants mentioned that they had received written material on post-stroke fatigue. The precise content of this material was not clear, but appeared to include information about the existence of post-stroke fatigue, its potential lasting effects, and common-sense advice on how it might be managed. Those who had received such material felt that it was on the whole helpful and reassuring.

*"I got this leaflet about fatigue after stroke. It made me realise that it's going to last longer than I thought... It makes you feel a bit more confident that you've got to take it as comes really and it's not going to get better overnight."* PP1135, female, 68 years

## **Discussion**

The day-to-day impact of post-stroke fatigue among our participants was high, with many different aspects of daily occupational performance and roles being affected. Our findings confirm those of previous qualitative studies that fatigue has a profound negative impact on stroke survivors' daily lives, and that stroke survivors are unprepared for the experience of fatigue (Flinn and Stube, 2010; Barbour and Mead, 2012; Kirkevold et al., 2012; White et al., 2012).

Participants generally reported that performance of basic ADLs was not affected by fatigue, but that more complex, energy-consuming IADLs (e.g. shopping, using transport) were more severely impacted. This may be because the effort required to carry out the former makes it difficult for stroke survivors to find the additional energy to engage in other 'discretionary' activities (Pallesen, 2014). Participants described their fatigue as being largely unpredictable, with variations in symptoms reported throughout each day and from one day to the next. These

findings are similar to those of Barbour and Mead (2012), who found that there was no particular time of day that patients felt most fatigued, and Carlsson et al. (2009), who found that stroke survivors have to manage an 'everyday life of uncertainty', due in part to their symptoms being unforeseeable. Moreover, this uncertainty about the level of fatigue that could be experienced day-to-day was itself sometimes cited by our participants as being a barrier to taking part in activities.

It is notable that, although our sample had mainly experienced minor or moderate strokes, the impact of fatigue was still high. In addition, the NotFAST study was unique in taking into account the association of depressive symptoms with fatigue, excluding participants who had reported depressive symptom levels consistent with a diagnosis of depression (score  $\geq 7$  on the Brief Assessment Schedule Depression Cards (BASDEC) (Adshead et al., 1992)). At six-month follow-up, the mean BASEDC score of those who were interviewed for the present study was 3.38 (SD 2.96), still well below this cut-off for depressive symptoms. Our findings, in contrast to those of other studies, may therefore be more clearly attributable to post-stroke fatigue rather than to concomitant depressive symptomatology. As we had excluded those with depressive symptoms, we are more confident of our findings. However, as people with aphasia were excluded from the NotFAST study and therefore also from this qualitative study, it may be that aspects of post-stroke fatigue specifically relevant to aphasia have been overlooked.

Our study was novel in exploring the strategies used by stroke survivors to self-manage their fatigue, thus addressing the paucity of qualitative literature on factors that influence post-stroke fatigue (Barbour and Mead, 2012). Self-devised strategies for managing fatigue among our participants included incorporating rest, accepting help from others, pacing activities, flexibility, altered priorities, and keeping active. These strategies may inform the design of interventions for fatigue. For example, interventions to promote activity after stroke, such as exercise programmes, have the potential to modify post-stroke fatigue (White et al., 2011; Barbour and Mead, 2012). Programmes to address emotional and behavioural responses to fatigue, such as motivational interviewing techniques, problem-solving, and/or cognitive-behavioural approaches, may be useful in helping survivors to interpret their new situation and its impact, and to develop adaptive strategies to enable participation in activities (Kirkevold, 2010).

It is notable that the management strategies used by our participants were sometimes conveyed as being more of an 'absolute necessity' or a 'last resort', rather than necessarily a conscious or



even always an effective strategy for managing fatigue. The contrast between 'pacing/energy conservation' (i.e. 'doing less') and 'keeping active' (i.e. 'doing more') as reported strategies for managing fatigue is interesting. There appear to be differences in individual approaches to fatigue management which reflect either 'active' or 'passive' responses. These may relate to the degree of control that people feel they have over their fatigue symptoms (Kirkevold et al., 2012), suggesting that differences in coping styles may have a bearing on the experience of post-stroke fatigue.

A striking common theme was the almost universal lack of education and preparation for the experience of post-stroke fatigue that participants received. Very few participants had spoken to a health professional about post-stroke fatigue and how this might be managed. The scant advice provided focused mainly on the need to rest, and participants were not given clear information on the likely prognosis of fatigue, but rather were left to navigate their own path through the problem of living with fatigue. Providing targeted information about post-stroke fatigue is likely to help survivors and their families to acquire a more realistic sense of the impact of fatigue and thus help to facilitate coping and prevent distress and burden (Flinn and Stube, 2010; Eilersten et al., 2013). A related issue is the need to identify fatigue in the early stages of recovery, this itself being a prerequisite for providing relevant and timely information to patients and families (White et al., 2012). It may be the case that professionals do not know what to suggest, and therefore do not discuss the issue of fatigue. A study by Rowat et al. (2016) has recently cited the research question, '*What are the best ways to manage and/or prevent fatigue?*' as the top research priority for nurses working in stroke.

As with other qualitative studies, our results represent only a snapshot of the experiences of a small number of stroke survivors. Our participants were relatively unimpaired physically and cognitively, having experienced mainly minor or moderate strokes, and were relatively motivated individuals, having chosen to take part in a research study. However, we found that fatigue was an important issue after stroke, even when stroke severity was relatively mild. Stroke survivors felt ill-equipped for the day-to-day impact of fatigue on their lives and often struggled to adapt. There is a need for improved information provision and educational interventions to equip staff and prepare stroke survivors for the impact of fatigue. The insights gained here should be used to inform the development of management techniques and interventions to reduce the impact of post-stroke fatigue.

## **Key points**

- The reported impact of post-stroke fatigue was high, even though overall stroke severity was relatively mild.
- Instrumental activities of daily living, leisure activities, social relationships and work life were all affected by fatigue.
- Stroke survivors felt ill-equipped for the day-to-day impact of fatigue on their lives and often struggled to adapt.
- Few participants had received any education or preparation relating to post-stroke fatigue.
- There is a need for timely information on fatigue to equip staff members and prepare stroke survivors and their families for its impact.
- Effective management techniques and interventions need to be developed, informed by the insights gained from this study.

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